

Legislative Program Review and Investigations Committee
Long Term Services and Supports in Home and Community Settings Study
September 21, 2016 - Public Hearing

Senator Fonfara, Representative Carpino, Senator Kissel, Representative Mushinsky, and distinguished members of the Program Review and Investigations Committee,

On behalf of the National MS Society, Connecticut Chapter , thank you for the opportunity to submit testimony regarding the PRI study on Factors Influencing Receipt of Long-Term Care Services and Supports in Home and Community Settings.

Our work in Connecticut advocating for long term services and supports goes back more than 20 years. Personally, in the early 2000's I was appointed as the family caregiver representative on the Long Term Care Advisory Council. I continue to serve on the Long Term Care Advisory Council and am a member of the Money Follows the Person Rebalancing Steering Committee and the Community First Choice Development Council.

Multiple sclerosis is a complex, chronic disorder of the central nervous system that can generate the need for a range of long-term care services. Twenty-five percent of people with MS need long term services and supports (LTSS) at some point during the course of their illness. LTSS must include both home- and community-based services (HCBS) and facility based care. Individuals need access to options across the entire continuum. Some examples services and supports that benefit people with advanced MS include home care, meal delivery, day programs, affordable home modifications and accessible housing, adequate funding for assistive technology, durable medical equipment and complex rehab technology, transportation, assisted living and skilled nursing facilities.

Since the Olmstead Decision, Connecticut has made progress in providing a variety of options for individuals. We are truly grateful and must acknowledge the outstanding support that the Legislature, Governor's Office and Department of Social Services demonstrated by creating an opportunity for

people with degenerative neurological diseases to remain in the community through the State Funded Connecticut Home Care Program for Adults with Disabilities (CHCPAD). Launched in 2007, it serves up to 100 people between the ages of 18-64 who have degenerative neurological diseases like multiple sclerosis, ALS, Parkinson's, early onset dementia, etc. This non-Medicaid program provides home-based services including case management to people who are at risk of being institutionalized in nursing homes. The target population includes individuals who have cognitive impairments as a component of their disability. CHCPAD is a critical resource for younger individuals with complex needs.

CHCPAD is only able to serve a small number of individuals and a limitation that participants can face is that the cost of a care plan cannot exceed \$2,909 per month.

For individuals with advanced MS, the physical challenges that come with the disease may lead to nursing home placement. Ultimately 10% of people living with MS are long term residents in nursing homes. They are younger more mentally alert, physically dependent, have more depression and stay longer than geriatric residents in a nursing home. Connecticut's [2013 MFP Closed Cases Report](#) specifically identifies multiple sclerosis as one of the conditions that remained a significant physical health issue for individuals who were unable to transition from nursing homes. The report continues with the conclusion that "other areas that may need to be addressed are services for persons with multiple sclerosis, lowering the incidence of falls in the community, and continuing to problem-solve for care plans over the cost cap. In 2013, at least one consumer was re-institutionalized due to an MS flare up and at least four others were not able to transition to the community because their care plan, which often required 24/7 assistance, was over the cost cap", pg. 9.

In our work, we continue to learn of individuals living with MS who are under age 65 and are unable to transition out of a nursing home because of their high care needs. Connecticut's Medicaid Waiver within the CT Home Care Program for Elders (Category 3) offers more extensive services than the Medicaid Personal Care Assistance (PCA) Waiver which serves those under 65. Category 3 of the elder waiver does not currently have a waiting list and individuals over age 65 who have the highest level of need are able to access services when they are found eligible.

The Medicaid PCA waiver for people under age 65 has an extensive waiting list. This wait list presents a barrier for individuals who need long term services and can lead to a person moving to a nursing home before a slot opens on the waiver.

Initially, Community First Choice seemed like it might offer a solution for those on the wait list. However, we are finding that people with MS and others with disabilities who have disability income that exceeds the HUSKY C level cannot easily access Community First Choice without a spend down or setting up a complicated trust. Under the Medicaid PCA waiver an individual is allowed to have a maximum monthly income of 300% of SSI or \$2,199.

We believe that people with disabilities who are under age 65 in Connecticut should have equal access under a Medicaid waiver to the same services and financial eligibility criteria as those which are available for people over age 65.

The effect of MS also takes its toll on families. Caregivers of people with MS spend about 24 hours a week providing care. Of these caregivers, 64% are emotionally drained, 32% experience depression and 22% have lost a job due to caregiving responsibilities. Family caregivers need supports through respite care and training in addition to flexible employment arrangements.

The scope of the PRI study is very comprehensive and this testimony addresses just a few of the factors associated with LTSS and the needs of people with multiple sclerosis. We look forward to working with the Legislature and the State to create a balanced affordable and accountable system.

Thank you.

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